Evaluation of Variables Affecting the Care of Patients With Sickle Cell Disease by US Location

Dr Julie Kanter
Associate Professor of Hematology and Oncology,
University of Alabama, Birmingham, AL

SCDAA 47th Annual National Convention, October 11, 2019
Disclosures

- Research funding:
  - NHLBI, HRSA: 1R01HL133896-01A1, U01HL133990-01

- Consultancy:
  - Bluebird Bio
  - Editas
  - GLG
  - Guidepoint Global
  - Imara
  - Jeffries
  - Novartis

- Steering Committee:
  - AstraZeneca
  - Novartis

- DSMB:
  - Sancillo

- Membership on a Scientific Advisory Committee:
  - AstraZeneca
  - BPL
  - Editas
  - Global Blood Therapeutics
  - Novartis
  - Modus
Background

• The state of care for individuals living with sickle cell disease (SCD) varies considerably across the United States
  • Numerous factors affect overall care for patients with SCD
  • Socioeconomic factors, access to care, and insurance coverage may be especially critical

• Hemophilia and cystic fibrosis affect <50% as many persons in the United States as does SCD\(^1,2\)
  • There are >130 comprehensive treatment centers for each of these diseases, with multidisciplinary teams providing quality care

• In contrast, health care providers with comprehensive expertise in SCD are scarce
  • This is particularly evident in low-income and rural communities with limited resources\(^3,4\)
  • Because of this lack of providers, persons with SCD often visit the emergency department (ED) or hospital for SCD-related concerns

• Most persons with SCD are publicly insured
  • Medicaid recipients with SCD may experience substantial barriers and delays to receiving necessary care

Objective and Study Aims

Assessing geographic variations in care for patients with SCD may allow us to understand where substantial gaps and disparities exist relative to the national average.

Understanding these differences can inform strategies to overcome challenges in care for patients with SCD.
Methods

• Patients with SCD were identified using a longitudinal analysis of a claims database\textsuperscript{a}
  • Geographic regions (geo-segments) with relatively high concentrations of patients with SCD were identified

• The state of care for patients with SCD in each geo-segment was assessed in 3 domains:
  • Socioeconomic factors
  • Access to care
  • Insurance coverage

\textsuperscript{a}Symphony Health PatientSource™, a highly representative, longitudinal claims database of ~300 million US individuals. May not capture all claims for a patient as individuals can enter and leave the sample over time.
Congressional Districts Were Used as the Basis for Geo-segmentation

Equal population units (~700,000) control for SCD patient density

Availability of rich demographics and socioeconomic data

Manageable number of areas
  • 436 congressional districts (CDs)
  • State-level analysis is too broad and misses regional population differences
  • Unlike metropolitan statistical areas, covers the entire US
190 CDs Were Selected, Covering 78% of US Patients With SCD

~83,000 patients with SCD who had ≥3 SCD-related diagnosis claims over a 6-year period (2012-2017) were included
Domains and Underlying Variables Related to SCD Care Were Identified for Analysis

<table>
<thead>
<tr>
<th>Socioeconomic Factors (General Population Level)</th>
<th>Data Sources</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Poverty level</td>
<td>• US census data (<a href="https://www.census.gov/mycd">https://www.census.gov/mycd</a>)</td>
</tr>
<tr>
<td>• Unemployment</td>
<td></td>
</tr>
<tr>
<td>• Education</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Access to Care (SCD Population Level)</th>
<th>Data Sources</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Hematologist-to-patient ratio</td>
<td>• Symphony Health PatientSource™ longitudinal claims database</td>
</tr>
<tr>
<td>• Patients using ED care only</td>
<td></td>
</tr>
<tr>
<td>• Overall treaters who are hematologists</td>
<td></td>
</tr>
<tr>
<td>• Hematologists specializing in SCD</td>
<td></td>
</tr>
<tr>
<td>• Access to a hematologist&lt;sup&gt;a&lt;/sup&gt;</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Coverage (General and SCD Population Level)</th>
<th>Data Sources</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Lack of insurance</td>
<td>• US census data (<a href="https://www.census.gov/mycd">https://www.census.gov/mycd</a>)</td>
</tr>
<tr>
<td>• Medicare vs Medicaid</td>
<td>• Symphony Health PatientSource™ longitudinal claims database</td>
</tr>
<tr>
<td>• Challenges/delays in access</td>
<td>• Descriptive assessment for delays</td>
</tr>
</tbody>
</table>

<sup>a</sup>Patients who visited a hematologist at least 2 times in the prior 15 months.
Variables Within Each Domain Were Compared With the National Average

Socioeconomic Score for *Sample* Congressional District

**Poverty**
- Below average = 1
- Above average = −1

% Below poverty line (households)

**Unemployment**
- Below average = 1
- Above average = −1

% Unemployed in labor force

**Education**
- Below average = −1
- Above average = 1

% Bachelor degree and above

Higher socioeconomic conditions
Variables Within Each Domain Were Compared With the National Average

Socioeconomic Score for Sample Congressional District

**Poverty**
- Below average = 1
- Above average = -1

% Below poverty line (households)

**Unemployment**
- Below average = 1
- Above average = -1

% Unemployed in labor force

**Education**
- Below average = -1
- Above average = 1

% Bachelor degree and above

Lower socioeconomic conditions
Each CD Was Characterized Based on the Cumulative Score Across the 3 Domains

- Scoring and segmentation
  - All domains were weighted equally, and all variables within the domain were weighted equally
  - CDs were scored based on their relative ratings across the domains and relative to one another

<table>
<thead>
<tr>
<th>Characterization Based on Scores Across Domains</th>
<th>CDs, n</th>
<th>% of Patients in Positive vs Challenged CDs(^a)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Generally positive: Higher domain scores in ≥2 domains</td>
<td>112</td>
<td>60.3%</td>
</tr>
<tr>
<td>More challenged: Lower domain scores in ≥2 domains</td>
<td>78</td>
<td>39.7%</td>
</tr>
<tr>
<td>Total</td>
<td>190</td>
<td>100%</td>
</tr>
</tbody>
</table>

\(^a\)Percentages represent proportions from the 190 CDs (of 436 CDs in total) included in the analysis.
Distribution of CDs Rated Positive or Challenged in Terms of SCD Care

Generally positive

More challenged
Districts With a Lower Ratio of Hematologists to Adult Patients Often Scored Lower Across Multiple Domains

**Ratio of Hematologists to Adult Patients**
- **High** (11 hematologists/100 patients)
- **Medium** (7 hematologists/100 patients)
- **Low** (4 hematologists/100 patients)

**Distribution of Positive/Challenged CDs**
- **Generally positive**
- **More challenged**

Strictly Confidential
Districts With a Lower Ratio of Pediatric Hematologists to Patients Often Scored Lower Across Multiple Domains

**Ratio of Pediatric Hematologists to Pediatric Patients**
- **High** (18 pediatric hematologists/100 pediatric patients)
- **Medium** (6 pediatric hematologists/100 pediatric patients)
- **Low** (0 pediatric hematologists/100 pediatric patients)

**Distribution of Positive/Challenged CDs**
- **Generally positive**
- **More challenged**

*Districts with 0 pediatric patients not shown.*
Additional Key Findings

• Reliance on ED care
  • The highest percentages of patients exclusively using ED care were found in districts with poorer socioeconomic conditions, less access to care, and less advantageous insurance coverage

• Insurance coverage and specialty care
  • In this analysis, insurance coverage did not predict access to a hematologist
  • In districts with relatively high insurance coverage rates, 17% of patients had visited a hematologist ≥2 times in the past 15 months, compared with 21% of patients in locations with lower rates of insurance coverage

• Substantial heterogeneity exists in socioeconomic conditions and access to care, even at the local level
  • Variations were observed between districts in the same state and between districts of some major cities
Limitations

• Incomplete sample of patients with SCD
  • Current analysis excludes ~20% of patients with SCD from 246 of 436 congressional districts

• Equal scoring of domains
  • Certain variables (percentage of households below poverty line, hematologist-to-patient ratio) may be more critical than others

• Geo-segments created based on *relative* differences
  • Creating geo-segments based on specific cutoffs (eg, X hematologists/100 patients, X% of treaters who are hematologists) may be more insightful
Conclusions

- The level of care for patients with SCD appears to be highly dependent on geography
  - Variations were observed between districts in the same state and also between districts of some major cities
  - Access to comprehensive care in SCD falls behind that of other chronic diseases, such as cystic fibrosis and hemophilia

- Areas with low hematologist-to-patient ratios often showed low scores across multiple domains
  - These districts likely have the highest-need patients
Conclusions

- New initiatives should be considered to address these disparities
  - Increase provider workforce – specialist training
  - Introduce telemedicine
  - Ensure health care practitioners in rural areas are capable of treating SCD patients
  - Local advocacy efforts in the most at-risk areas
BACK-UP
Districts were assigned ratings based on percentage uninsured and Medicaid patients vs difficulty of access.

<table>
<thead>
<tr>
<th>% Uninsured + Medicaid Patients</th>
<th>Challenges/Delays in Access</th>
</tr>
</thead>
<tbody>
<tr>
<td>Below average</td>
<td>Low</td>
</tr>
<tr>
<td>Above average</td>
<td>High rating</td>
</tr>
<tr>
<td></td>
<td>Low rating</td>
</tr>
<tr>
<td></td>
<td>Low rating</td>
</tr>
</tbody>
</table>

High rating: 20
Low rating: 20
Medium rating: 20
High rating: 20

Strictly Confidential